Is Design as a practice completely outside the language of Care?

Does Design Care...?!

Head-to-Head Debates

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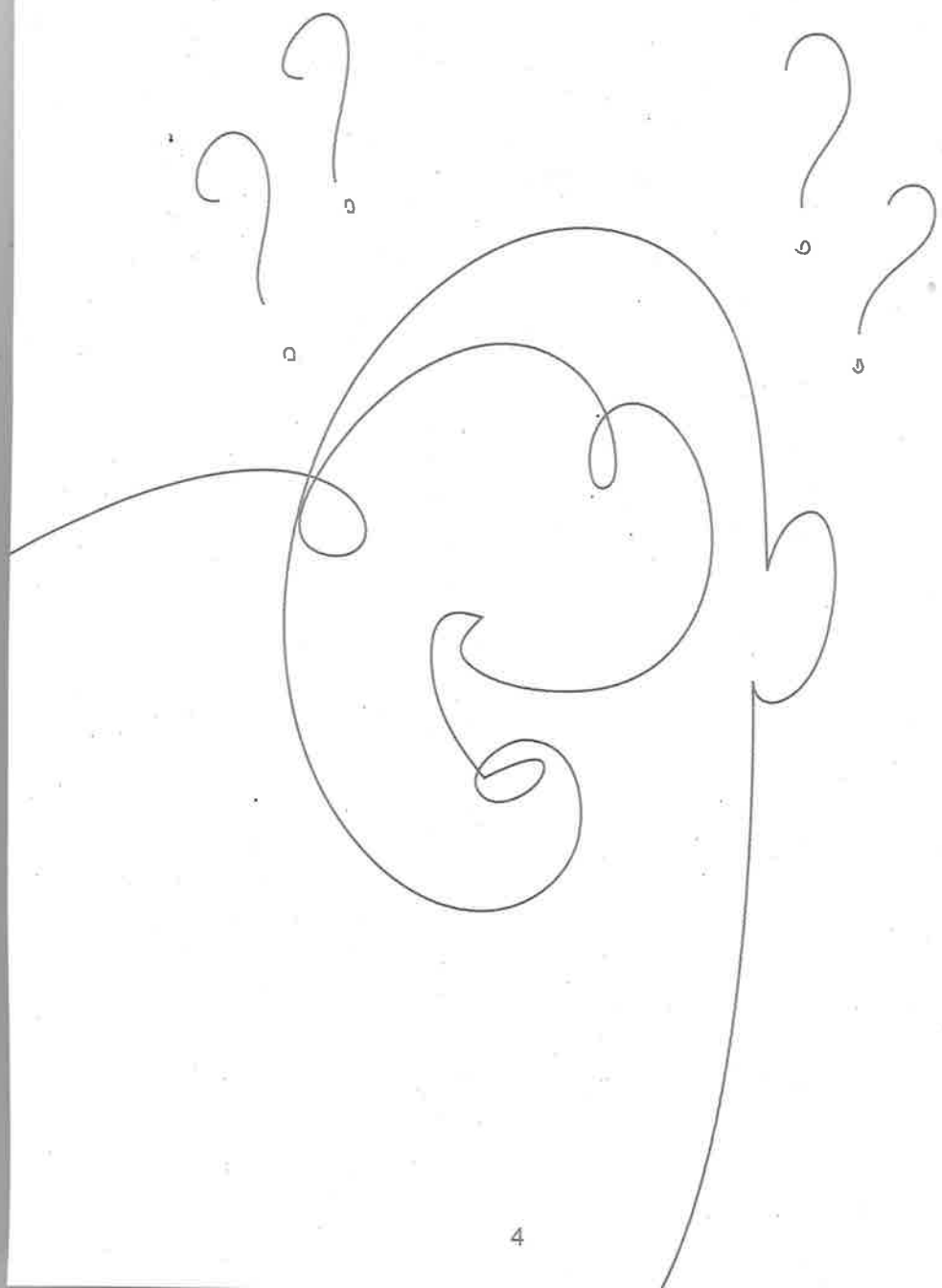


Introduction

In 2017 the first Does Design Care...? workshop at Imagination Lancaster asked a series of question that were eventually addressed in both the publication of the Lancaster Care Charter (Design Issues 35:1 2019) and the DDC…? Book.

Similarly, in 2019 the second Does Design Care…? workshop in Chiba, Japan, asked more questions but this time the questions came from the participants. To participate in the Does Design Care [2]…? workshop applicants had to send a 1000 word position paper from which a number of questions emerged; questions we thought needed debate not just discussion (a bit of a beating rather than a mere shakeup). The questions are listed at the end of this introduction. It is important to make clear the questions arose from what the participants were saying. In order to familiarise themselves with the questions they were sent to all participants in advance

of the workshop. On the first morning of the workshop participants were randomly paired for what we called Head-to-Head debates. Each pair was randomly assigned one of the 25 questions to explore and contend in greater detail. They were required to record (audio, notes, images, examples) their debate and at later stage in the workshop each pair presented what they had been debating to the rest of the participants. After the workshop each pair had to transcribe, edit, and enrich with visuals, their debate, all of which has been collected into this publication.

Like the first workshop in Lancaster the Chiba workshop was a thinking, making and doing workshop that explored different ways to explore, conceptualise, provoke, contest and disrupt care, and the various outputs serve to synthesise future visions of care. Unlike the Lancaster workshop; a strong conviction coming from the participants was that design can and does empathise and therefore design can and does care. What-design-can-do is embedded in its historic belief in the design of what-might-become. But as we have written elsewhere (?remember where?), in reality design's future has to confront what-might-not-become. And what-might-not-become has to confront the uncomfortable reality that design might not be able to do what it believes it can do. Care, being invisible, is a good test for what in reality design can do. Rebecca Solnit questions empathy when she writes "There's a currently popular argument that books help us feel empathy, but if they do so they do it by helping us imagine that we are people we are not". For design to care through empathy it might just be that design, continuing to advocate what-might-become, is producing designers who imagine they are people they are not.

We have asked before whether design's attraction to care is just opportunistic. And we wonder whether the allure of empathy for design to want to transact with care because, care is becoming elitist as Yuval Harari explains,

"because it rejects the idea of a universal standard applicable to all, and seeks to give some individuals an edge over others. People want superior memories, above-average intelligence and first-class sexual abilities."
(Harari, Homo Deus, p6)

Foucault pointed out that diagnosing what is ill is always equally about enforcing what is healthy. These workshops have been diagnosing whether design cares and in this sense they have also been enforcing what-might-become of design.

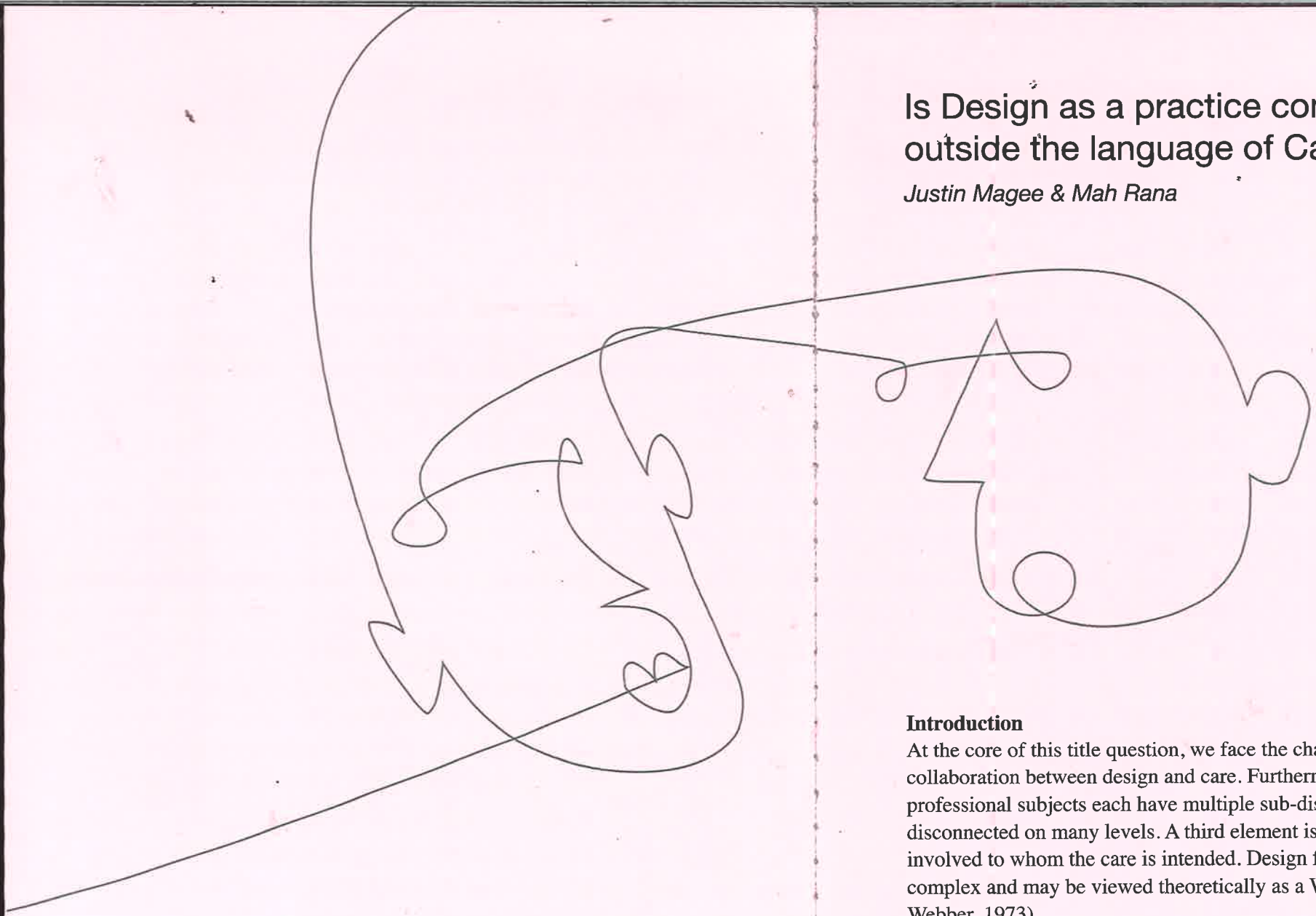
Rebecca Solnit, Men Explain Lolita To Me, Literary Hub, December 17, 2015
http://lithub.com/men-explain-lolita-to-me/

Yuval Harari, Homo Deus: A Brief History of Tomorrow, Harvill Secker 2015, (p6)

MISSING REF

For this edition of Does Design Care...?!, we had a few questions we wanted the participants to reflect and discuss upon. The participants were divided into pairs, each pair was handed a question to use as a conversation starter. The list of questions included the followings:

What was Design doing before it latched on to Care?
Should Design Care?
What was Design doing before it latched on to empathy?
Where will all of this caring get us?
How might we best Design Care?
How might we best Bespoke Care?
What should we (Design) care about?
What should we (Design) not waste our time caring about?
Are there Care priorities for Design? If so, what are they and why?
What kind of trade would a "Care Trade" look like?
If Designer and User continue to have some form of relationship what future might Design and user Care for?
Is it possible for Design to operate in a context where we choose not to Care?
How might Design avoid the overdevelopment of Care?
Is it possible that Design & Care might sometimes produce a negative result (which means being uncaring or careless)?
Can Design Care for people's frustrations and doubts?
Is the invasion of Care by Design just another colonising fantasy?
Can Design empathize? If so, where does all this empathizing get us?
Despite the optimistic predictions for the Design of Care what does the doing of Care really do?
To look at the future of Care which is best - Design fiction or Science fiction?
What role does Design play in the gesture of Care?
Will Designing Care eventually medicalise Design?
If one were to explore the relationship between social value and the value of Care what might you get?
Is Design as a practice completely outside the language of Care?
Can Design's idealistic claims of true inclusion ever be achieved?
Can Design contribute to the gap between the ideal of Care and real Care?



Is Design as a practice completely outside the language of Care?

Justin Magee & Mah Rana

Introduction

At the core of this title question, we face the challenges of inter-disciplinary collaboration between design and care. Furthermore, these academic and professional subjects each have multiple sub-disciplines, which are often disconnected on many levels. A third element is the diversity of the people involved to whom the care is intended. Design for Care is inherently complex and may be viewed theoretically as a Wicked Problem (Rittel & Webber, 1973).

This article will navigate through the Head-to-Head discussion between a dementia-carer, psychologist and designer with an experienced product designer and researcher who has worked in care and health related projects (M. Rana & J. Magee, 2019, personal communication, 1st July). They consider both the harmonious and dichotomous relationship. Their

independent viewpoints find commonality and lead to adapted models for proposed engagement across sectors and disciplines. In immediate response they cite two points of reference.

"Design is people" (Jane Jacobs)
"Good care is about people" (WHO, 2008)

Are we speaking the same language?

In some parallel to the question posed, Rittell & Webber (1973) suggest that the problem-solving approaches of Science and Engineering as inapplicable to societal issues. Is Design and Care the same, does a gap exist? Farrell and Hooker (2013) contextualise that through time, practices have evolved. They quote Cross (2007), explaining that the distinction between design and science problems were related to being contrastingly perceived as ill-defined verses mere puzzles. Cross (2007) goes on to explain that it was only in the 1980's that Design Research "came of age" and that "there are designerly ways of knowing" which continue to evolve. Farrell and Hooker (2013) explain that science and engineering has also evolved and that now, while different approaches may be used, they share similar and accepted core problem solving principles. Shifting perception's is important in collaboration. From the outset our Head-to-Head debate began to interrogate this potential issue.

MR: *Because when I saw this [question] I was thinking what is the language of design and care? And that it's useful to unpack the question first and view it from different perspectives for example from a medical perspective, government policy perspective or from the carer or the person being cared for. And in this sense perhaps there are different languages?*

JM: *And I guess from a [design] perspective that's your users? Singularity within the language of care and the practice of design exists. However, we propose there are many singular languages co-existing but in a parallel way. This is where siloed responses to the clinical issue or mis-direction of the design solution can result. We consider the overlapping model of care and design (Fig. 1), with people at the intersection. We propose that as design and care increasingly overlap a more holistic view of the person for whom care is intended is achieved. Adversely as*

design and care laterally move away from each other, into their individual disciplines or silos, then they move away from the needs of the person. This quadrant model also considers that a range of positive and negative user experiences exist that design and care must negotiate. This relationship needs to consider both the positive and the negative experiences of people (UX), aiming to remain close to the nexus of this quadrant graph.
As different professional disciplines evolve in design or healthcare they are similar to rivers and tributaries relating to a singular parent discipline

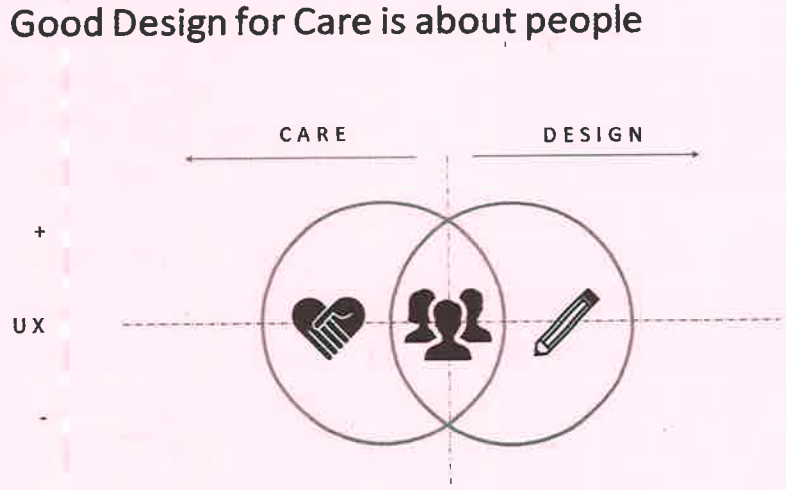


Fig. 1 Good Design for Care is about people inter-disciplinary ecosystem

(Fig. 2). These singular pathways can influence the outcome. For instance, within design, if a GUI designer is asked to solve a problem they are likely to develop an app as the solution as articulated in case studies by Krishna (2015, p5-21), even though some other intervention may be more appropriate. He captures this issue well in the title of chapter 4 "UX≠UI, I make interfaces because it's my job, bro" (Krishna, 2016, p45). This idea that a designer has an expectant delivery, can steer them away from the actual issue as we discussed:

JM: *Don't chase the solution…That's actually a challenge for many designers, because designers are solution driven.*

MR: *And that, that could be, not disruptive, but that could actually be…*

JM: *Harmful?*

MR: *Yeah, harmful, and also, health professionals, you know, they kind of look to kind of prescribe something, but that that can also, be [harmful], So solution driven strategies can be harmful…or can do more harm than good.*

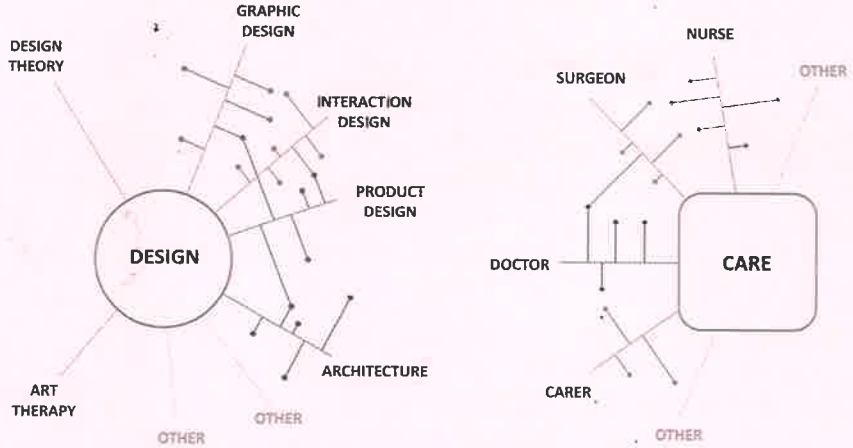


Fig. 2 The singularity of design and healthcare professions.

As discussed, the carer can also be driven by evidential science, recommendations, anecdotal testimonies or external demands which are applied with singularity. The discourse changes depending on the viewer perspective, for instance the healthcare professional or department who will have to engage in change (with targets?), the receiver of care (with trauma?), the carer (emotively connected?), the designer (with a financial stake?) etc.

We contextualise the complexities of design for care using a model with a specific scenario of care following an event of stroke, were the person is central. This model is an extrapolation of Saffer's (2010, p21) model which demonstrates the professional disciplines associated with interaction design (Fig. 3). Our example (Fig. 4) is derived from empathetic modelling conducted with the Western Health & Social Care Trust, Children's Stroke support unit (2017).

We propose that disciplines of design and care should be considered as a combined model, which considers the harmonious interdisciplinary relationships of professional disciplines surrounding design for care. In each case the specific nature of the care event and the design expertise required (or other discipline) should be connected (Fig. 5).

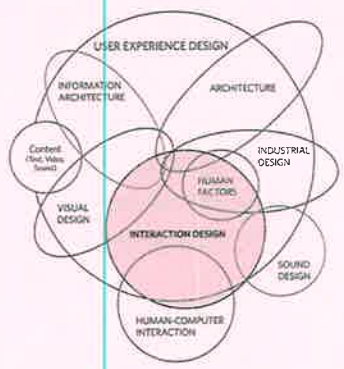


Fig. 3 The Disciplines surrounding Interaction design (Saffer, 2010)

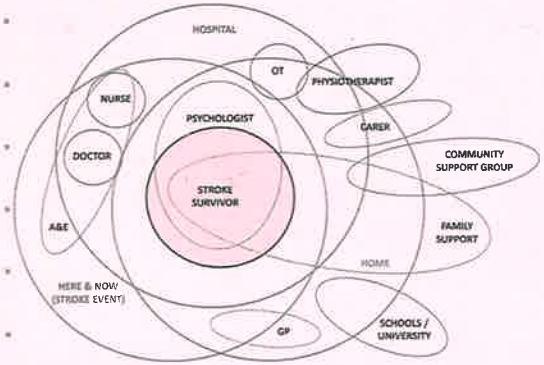


Fig. 4 The complexity of care, following the event of a stroke inspired by Saffer (2010).

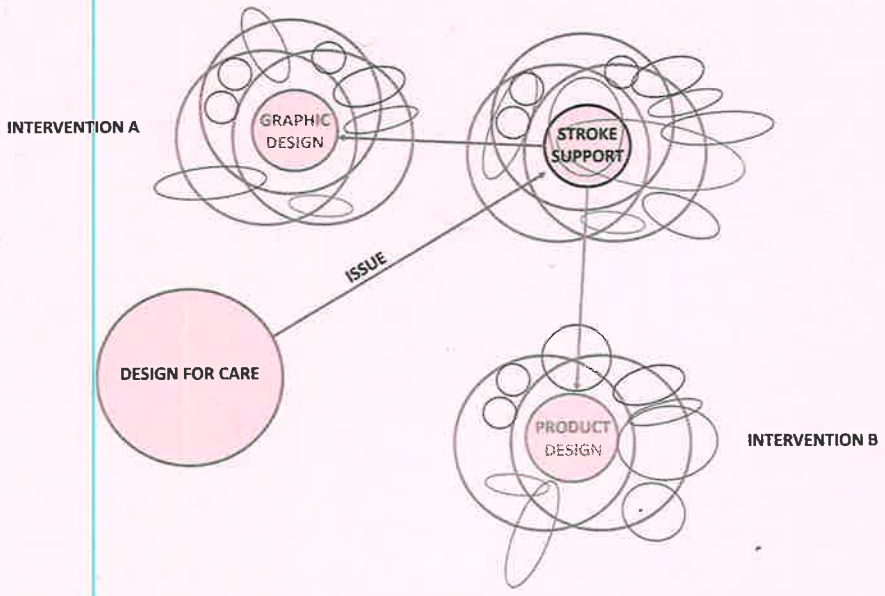


Fig. 5 Design for Care Interconnected model, using selected interventions for stroke support

One of the issues that transpired from our discussion was that the language of care has become over medicalised. As such, hierarchies of knowledge

exist rooted in their respective professional disciplines. These related, but different languages provide extra barriers at different touch points. The imbalance of medial phraseology verses lay understanding may impact on the capacity for the individual to individual to self-care, as well as advocating for another person's care, through lack of comprehension. Cultural variation can add another layer of complexity in communication. These hierarchies of knowledge can manifest in hierarchy of esteem, where egotistical traits may be observed. This characteristic is counter to empathy building. Professional medical staff may be excessively factual and direct in circumstances where softer communication skills and lay language are required. Similarly, there is a responsibility for the person being cared for, their carers, and designers, to become knowledgeable within the particular system of care.

Habitual practice exists within medicalised care. While many of the principles or methods are grounded in science based on evidence-based research, or evidence-based practice, these habits should not assume singular approaches, without understanding the individual. Similarly, science is in constant change as new knowledge is shared. Habitual behaviour may also affect the person being cared for. If they become dependant on or believe they need a particular medicine, this may become part of their identity. Does this lead to other psychological issues?

JM: *It may lead to a reliance effect, and maybe an, 'I am sick' effect.*

MR: *Doing things like crafting, or physical movement or stuff like that, those activities can increase serotonin levels … and can reduce the need for pharmaceuticals or reduce the dosage.*

These issues are both biological and psychological in their complexity. There may be monetised issues within healthcare. These may link to big Pharma influence, funding and in worst case corruption. Or the oversupply of less effective pharmaceuticals or not choosing the best medicine in case a less expensive one works best. The healthcare systems find themselves within a monetised cage.

MR: *Where care is profit and loss. It becomes a profit and loss… or the*

priority for care becomes profit and loss.

JM: *Often if the NHS finds something that works, then on mass, they all use it…that is 'the' supply chain and therefore it does not chance.. from my point of view as a product designer, if I can get a product into the NHS then that will make money for the company I work for, because they [NHS] will not chance…that's a bad driver…but a realistic challenge in the world of care.*

MR: *It's a neo-liberal model, where care is monetised…it is profit and loss basically…the priority of the care can become profit and loss, rather than the person.*

The Francis (2013) Report has been pivotal in stimulating change in the NHS. In its executive summary this monetised issue is highlighted:

"This failure was in part the consequence of allowing a focus on reaching national access targets, achieving financial balance and seeking foundation trust status to be at the cost of delivering acceptable standards of care." (Francis, 2013)

The systems of care are also challenged, highlighted by the inefficiencies through lack of order in record keeping to gaps in connectivity between different partners managing the care of individuals. There may be poor communication between interdepartmental agents within a Healthcare provider, or poor collaboration between different types of care organisations. This is a web of siloed interactions, where individuals receiving care may have variation in treatment partners. The silos that exist can be divisive from the perspective of the person being cared for. This issue is raised in item 1.114 of the Francis report as being one of the reasons why certain issues were not discovered earlier. In a challenging financial and political climate there is an overarching layer of complexity which is caused by a culture of fear within healthcare. This ranges from concerns about job cuts to litigation around care that may deviate from the habitual model.

Design practice has several challenges when it tries to care. Designers by

their nature are empathic. They are passionate about the work they do and through the creative process gain a strong sense of ownership and pride for the work they produce. While a strength, this also has its downfalls which include over optimistic promises or idealistic proposals which may not become realised. It too can introduce egotistical behaviour. For instance, when the designers create a proposal, they can subjective and experience a sense of ownership. This may lead to a biased desire for that design to be used, with risk of superseding the user's need.

Design works within a monetary framework. The designer is a paid consultant. This can lead to the withdrawal of service, activity or product if the resources cease. Managing true co-creation is a real concern when designing for care, to ensure the right design for the right problem. If design operates within its specialised discipline, then singular solutions are more likely.

Farrell and Hooker (2013) distil three conditions for wicked problems in Design and Science, which relates to Rittel & Webber's ten component model of wickedness-making features. They propose that these are commonalities between design and science. These are: Finitude of our cognitive capacity and resources that are limited as individuals, society and humanity; Complexity of interactions associated with the nested hierarchies, systems and cascading feedback/forward loops, within contexts of being history-dependant, having unpredictability and perhaps irreversibility; Normativity and human values can be intertwined within the formation of a problem and the development of solutions where compromise if a feature.

Reflecting on language and practice of Care and Design, a clear dichotomy can be seen between their respective eco-systems. However, commonality does exist.

MR: *It's a relationship?*

JM: *Yeah.*

MR: *Yeah. You have to build relationships and trust.*

A Model for Open Source Care

One of the primary issues in the design of systems, services and products for care is that these are within a monetised framework, relating to profit and loss. A design consultant or agency is employed on a financial contract that has an associate time restraint. Clinical practitioners must meet a range of targets associated with the business of care. Each of which is limited to what Farrell and Webber refer to as Finitude. As such the scope and extent of the solution is always limited. Furthermore, indicative to design there is a deep relationship developed with any project/client and a passionate engagement during the creative process, which leads to a sense of ownership.

Similarly, there is a financial burden on the carer, who may have reduced capacity for income generation which has a related effect on their time and freedom to care for themselves. They too have a personal commitment and passion connecting them to the cared-for individual. Collectively these financially rooted issues lead to real barriers in care development and emotional engagement to biases.

During the Does Design Care 2...? Workshops the idea of Care Trade was suggested. In our view, while the ethos was well meaning, the emphasis of the term "trade" we disliked as its connection with commercialisation and retail are firmly rooted. A more shared model can be achieved.

JM: *I actually do a number of projects where I've wavered the money. We do work agreed as contract research at a set amount. The money comes in, and back out to the project, but we share the IP...the IP is a currency, a value to allow the university to allow me to do it. I don't count the hours [of work], I just try and make the best design I can for that particular need. Maybe it's a better model, it's a more honest model? It becomes research rather than consultancy.*

This model takes longer, but typically leads to deeper thinking, more investigative research leading to the right design following a clearer and iterative enquiry of the right problem.

JM: *We need models that have an infrastructure that allow designers to*

engage with care. Actually, a care need...it needs to be beyond designers...a consortium...a community ... designers can't own this neither..."

MR: Yeah, A resource like 'the commons'...? An open care version of Creative Commons.

Within software development, the Free and Open Source Software (FOSS) has led to a disruptive change in the industry model, where Intellectual Property is released in order to develop an environment of sharing. This has resulted in significant growth of the quality of code readily available for those who engage within this principle. In turn more complex solutions are developed at much greater speed and better chance of uptake. Wang et al (2012) outline that while the industry has been transformed, many FOSS initiatives may fail. They outline successful approaches, which require both process-level and project-level measures and outcomes. In nature these need to be adopted and retain activeness and provide definitive benefits and technical successes. Their foundation is one built on social capital where "relational assets (e.g., trust, gift giving, obligation, and reciprocity)" are among the main drivers. Researchers in FOSS initiatives are reported to dedicate time and energy to the tasks required and promotion of the project, generating larger acceptance rates. Direct correlations with the size of the internal and external FOSS network and the success has been established. User engagement and participation builds trust, loyalty and better-quality outputs. In reflection of the current problem and applying this human agency model, a applied framework for 'Open Source Care' is proposed as a creative commons model. It should not be owned by any one sector, as this leads to territories and in turn silos. It should involve all stakeholders and pivot around those who are cared for.

This model is based upon an extension of the designer-client relationship to multiple designers, multiple clients and expert voices. We've based it upon the Double Diamond model of the design process (Design Council, 2005), this adaptive model takes the metaphoric form of a jellyfish, which in nature effectively spreads its tentacles to efficiency forage for food. In our model, the body hosts the iterative process of hyper-cyclic design and iteration, shaped by a range of stakeholder views. Each diamond phase represents oscillations across the stages of the design process (discover, define, develop and deliver) and cyclic evaluation. The contributions from stakeholders has a flexible chronology depending on the professional need. The tentacles represent the gradual refinement of multiple solutions (Fig. 6). As each co-operative of professionals are 'sprinting' in tandem providing an array of ideas, 'hitchhiking' on the work of others, the process is accelerated. Another layer of the process is the iterative feedback loop from carers and health and social care professionals providing guidance, critical review and co-creative practice towards solving unmet needs. Three possible financial enablers are considered to make this proposal viable. The first enabler we propose is that in return for time dedicated to a defined priority care issue companies consider the UK Government R&D tax credit incentive.

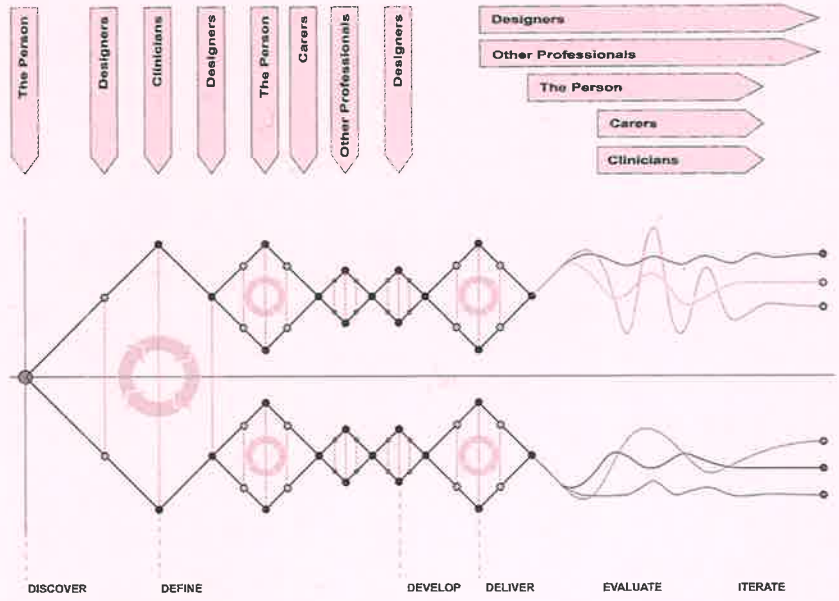


Fig. 6 The Open Source Care process framework.

The second enabler involves larger organisations and universities or others with the capacity to 'donate' time as part of their remit. Their role may help with a range of issues from embedding research knowledge or emerging technologies into the development pipeline; supporting ethical approval processes or large-scale work-based learning involving students or researchers.

The third enabler involves those volunteering as carers, and those who are cared for. These are the most critical voices who have deeply experiential views of the issues. They provide precision within a complex process towards the bespoke and perhaps ideal needs, yet with an achievable resolve. Treating the carer and person cared for as expert users is key. We propose that an initiative is needed so that the carer, voluntary worker or cared for person could earn credit for a valued service in turn for their knowledge exchange. This may be access to counselling, free sports membership or cinema tickets.

Returning to the question *Is Design as a practice completely outside the language of Care?* - it can be if mistreated. In reflective review of Wicked Problems theory, Coyne (2005) concludes his many views considering the implications for design. One notable comment relates to the professional operationalisation of such contemporary theory asking, *"Are these concepts waiting to be identified in language, or are they created through the discourse?"*; Coyne explains that talking is a form of action. In context of Design for Care, communication and sharing of methodologies especially through participatory inquiry, exploration or iterative practice forms part of the conversation where the language of Design and Care will continue to converge. Real progress can only be made when design disciplines refrain from working in isolation, and health and care disciplines simultaneously engage in interdisciplinary knowledge exchange. Such progression in tandem with human agency can lead to sustainable 'Open Source Care'.

Coyne R. (2005) Wicked Problems Revisited, Design Studies, Volume 26, Issue 1, January 2005, p5-17 https://doi.org/10.1016/j.destud.2004.06.005

Cross, N. (2007). Forty years of design research. Design Research Quarterly, 2(1), p2-5 https://doi.org/10.1016/j.destud.2006.11.004

Design Council (2019) What is the framework for innovation? Design Council's evolved Double Diamond, [Available at:] https://www.designcouncil.org.uk/news-opinion/what-framework-innovation-design-councils-evolved-double-diamond, Accessed 22 September 2019

Farrell R. & Hooker C. (2013) Design, science and wicked problems, Design Studies 34, p681-705 http://dx.doi.org/10.1016/j.destud.2013.05.001681Ó2013

Francis R. (2013) Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry. London: The Stationery Office.

Krishna G. (2015) The Best Interface is No Interface: The Simple Path to Brilliant Technology. New Riders, USA

Jacobs J. (2019), Jane Jacobs Quotes, BrainyQuote.com, BrainyMedia Inc., https://www.brainyquote.com/quotes/jane_jacobs_169648, accessed July 2nd, 2019.

Rittel, H., & Webber, M. (1973) Dilemmas in a general theory of planning. PolicySciences, 4, p155-169 https://doi.org/10.1007/BF01405730

Saffer, D. (2010) Designing for Interaction: Creative Innovative Applications and Devices, 2nd Edition. New Riders, Berkeley, CA

Wang J., Hu M.Y., Shanker M. (2012) Human agency, social networks, and FOSS project success, Journal of Business Research Volume 65, Issue 7, p 977-984 https://doi.org/10.1016/j.jbusres.2011.04.014

WHO (2008) The World Health Report 2008 - primary Health Care (Now More Than Ever), World Health Organisation